

Testimony of Barbara Maizie
The Arc of California
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Good morning. I'm Barbara Maizie with The Arc of California. Thank you so much for holding this hearing and for the opportunity to participate. The Arc is a membership organization, and while most of our local chapters provide direct services, the Arc is led by family members and consumers. It is their points of view that I'll be representing today.

But as someone with over 35 years experience in this field in California, there are other perspectives that I bring to this discussion. I currently serve as the chair of the public policy committee of CDSA, the California Disabilities Services Association. CDSA is a statewide organization of service provider agencies. These are local, mostly non-profit agencies from which regional centers purchase services, often referred to as "vendors" in the audit report. These local agencies are really the "front line" of the system. Many of them were in existence before the Lanterman Act was passed, and long before Regional Centers were created.

I also bring the perspective of someone who has been the Executive Director of The Arc in Contra Costa County for 24 years, during which time the agency has grown to where it now serves over 1000 children and adults every day in a wide range of services and supports. My role there, as well as my service on the board of directors of two other local service agencies has given me an extensive education about how service providers and regional centers can work together very well, or sometimes not very well at all.

I know that this hearing is about fixing "problems" in the system, but I think it is very important not to let those problems overshadow the larger picture. California's system of services and supports is unique, and from the family and consumer perspective it is without a doubt the best system in the United States. California is serving 240,000 people while other states have ten's of thousands on waiting lists. We are serving them at in a privatized, highly cost-effective, community system where the per-capita cost is among the lowest in the U.S. Of course there are problems in the system, and we must address them, but I think it's important that we not let them overshadow the true value of the Lanterman Act and its promise to California.

So now, about those problems: In spite of all the good that this system is accomplishing every day, I must tell you that the community concerns that led to the need for this audit are very real. My experience in the last week has been a testimony to that. I have received phone calls from people all over the state who heard I was going to be on this panel and wanted to advise me about what to say, and not say. The comments I got fell into two categories.

Category 1 said: Please tell the joint committee members that our problems with our regional center are very serious. Please don't whitewash the issues. If we don't tell them now, in response to this audit, we'll never get the legislature's attention again. These

folks are extremely grateful to Mr. DeLa Torre's committee and to the BSA for their work on this issue.

Category 2 said: Please don't say anything critical about the regional centers! It will just make things worse and the regional center will take it out on us. (These comments came from both providers and family members). These folks are extremely afraid of retaliation by their regional center.

Of course I have to assume that there is also Category 3 and that would be the people who heard about the panel but didn't call me. Things are probably going along reasonably well for them. It is very important to keep a sense of proportion about this. Not all regional centers are the same, just as not all service providers and not all families are the same. And the impact each regional center has on its community depends very much (far too much, actually) on the personalities of the top management staff at any given time. My personal belief is that on the whole, the majority of people and providers find a way to work cooperatively with their regional center. But it is important for the committee members to know that there are many family members and service providers who feel they cannot speak up for themselves because of the power their regional center has to do harm to them. Sadly I must tell you that there are many people who feel this way, to a greater or lesser degree, in every regional center area. The need for improvements is very real, and people all over California are hoping that this hearing will be the first step in a process that will lead to meaningful change.

So given all this input, I had to decide what to say to you today about the results of the audit. That hasn't been easy.

Reading the audit I kept thinking about how the recommendations mesh with some of the basic components of the California's developmental disabilities system:

- The system was designed very intentionally to insure local control and to build in flexibility so that regional centers could be responsive not only to local needs but also to individual needs. .
- The system was designed in a way that creates a natural and unavoidable tension between various players: DDS, regional centers, services providers, and families.
- The system is exceedingly large and complex. Some of our regional centers serve caseloads that are greater than those of entire other states.
- We tend to talk about "regional centers" as a group, or "vendors" as a group. But in reality they are not all the same.

In such a complex system, things are interrelated and every change or "tweak" has a domino effect. Without a deep understanding of how the system works, it is very difficult to predict the consequences of any change and whether it will have the intended effect, or not. Somehow we need to find solutions that avoid excessive bureaucracy, preserve the needed flexibility for regional centers, but also insure statewide fiscal and programmatic integrity. It's a tall order.

The auditor has categorized the recommendations into 3 general categories or chapters, but looking at them from point of view of the community, they fall into 3 slightly different categories:

- 1) Those that are solely administrative,
- 2) Those pertaining to the whistleblower issue, and
- 3) Those that have a substantive impact on consumers, families and service providers.

I have comments on each of these three categories of recommendation:

- Those that are basically administrative in nature and have to do with administrative oversight of fiscal and compliance issues at regional centers. These include insuring RC audits every 2 years, insuring proper back-up documentation for POS purchases, insuring that invoicing documentation meets the requirements of the Medi-caid waiver, and correcting several specific instances of questionable actions by particular regional centers. All of these recommendations and the department's responses seem reasonable and appropriate.
- Those that pertain to whistle-blower protection for regional center employees. This is something that people in the community very much want to see strengthened. Actually many families and service providers want to express their concern that the same protection from retaliation by regional center should be extended to them as well. This does go beyond the scope of the audit, but it has been mentioned so many times that I felt I should report it to the committee. I should also mention that in community discussions of this issue the subject of the need for increased transparency by regional centers is always mentioned as being a high priority. But whether the response of the Department and the regional center to this recommendation is adequate is a matter that is better determined by those who are expert in the subject of method of whistleblower protection.
- There are 3 recommendations that are of great interest and concern to people in the community. I want to give those the most attention. These are recommendations that we see as very substantive in that they have a direct impact on consumers, families and service providers. These are the recommendations pertaining to:
 - 1) assuring the reasonableness of negotiated or otherwise established rates,
 - 2) requiring documentation of the vendor selection process, and
 - 3) defining a process for procurement of services.

The main reason for our concern in these areas has to do with the sheer complexity of the issues involved. People are not sure that these recommendations will achieve their intended outcomes, or that if they do, some of the underlying problems that led to this audit will still remain unaddressed. I'll give you examples of what I mean in each of these 3 areas:

- 1. Rates: I operate an agency with at least 40 different vendorizations. Each vendorization has a different rate attached to it. Any normal person who came and looked at the various services and program designs and rates would conclude that the rate system that set the rates was grossly inequitable and made absolutely no sense. And they would be right. Except for one thing: There is a valid explanation for every one of those rates that is totally legal and procedurally sound. They were set at different times, under different regulations or laws, sometimes decades apart, and unless you know the background they make absolutely no sense. Some of them were established by law, some were based on cost statements and some were “negotiated” with the regional center. But these are services that are being developed to help support individual lives – individuals with very different needs and very different circumstances. There simply is no way to look at a process on paper and know if the rates are reasonable, or if favoritism or a conflict of interest was involved in the process. However, there are actions that could be taken to bring more “reasonableness” to the process, but we believe specific recommendations would be best developed by a small group of individuals who are very experienced with the different methodologies now in use and who could determine which kinds of actions would produce the desired result.

- 2. Vendor Selection: The recommendation requiring documentation of the vendor selection process is one that is of extreme importance to families, consumers and service providers. This is at the heart of the individual program plan process that is the core of the promise of the Lanterman Act. We are concerned that the requirement to document the process will not have the desired result and will, as DDS indicated in their response, potentially cause significant delays in the provision of needed services. At the same time, issues around service provider selection in the IPP process are central to the problems families experience. On behalf of many families, the service provider community and The Arc of California I would like to suggest an alternative recommendation – greater DDS oversight to insure that regional centers consistently follow all aspects of the IPP process as defined in the Lanterman Act. This type of oversight would be the most appreciated and valued outcome possible for the people this system was designed to serve. I should also mention that The Arc of California believes that because this is a request for DDS to provide greater oversight of the IPP process (not its content or outcome) that it is totally consistent with the ARC vs. DDS Supreme Court decision of 1985.

- 3. Procurement of Services. This recommendation is also of concern for several reasons: the extreme complexity and variety of services that regional centers must obtain, the often emergency nature of needed services, and the challenges of the local “market” in various geographic areas. It would be extremely difficult to design a process that is flexible enough to be responsive to local needs while structured enough to assure sound management, equity and fairness to potential vendors. We also noticed that the use of the term “contract” in several places in the audit report indicated an assumption about the system that is not accurate. Here again, as with the issue of rates, we believe that specific recommendations would be best developed by a small group of individuals who are very experienced with the different procurement methodologies now in use and

who could determine which modifications would be most effective in achieving the desired results.

We hope the joint committee will consider our suggestions in these 3 substantive areas.

In closing, I want to mention that many people in the community are wondering what happens next with the results of this audit. Based on my own experience, I believe one of two things will happen after today:

One option is that individuals or groups will leave this meeting and go about the process of sponsoring legislation to address whichever issue is most important to them. This will result in the usual political processes and the usual struggle of some parties to support the bill and others to get it killed. And we'll see a process similar to what we saw with AB 435 and AB 2220 earlier this year.

The other option is what I'm proposing. I honestly think that there are really only 4 or 5 individuals in this entire state who have a sufficient depth of experience and knowledge about the way regional centers and service providers interrelate to be able to propose actions that will achieve the intended, rather than other unintended, results in the substantive areas, and bring the needed system improvements. If those 5 people came together, preferably with the blessing of the joint committee, and developed some practical, workable suggestions in the areas I've identified as 'substantive', we could find ourselves with improvements that will work, and that everyone can live with. These individuals must be people who are very familiar with the functioning of regional centers and service providers, who have a strong commitment to the principles of the Lanterman act, who have a deep respect for the intrinsic value of the system that is now in place, and a deep respect for the need for cost effectiveness in the current economic climate. I hope that those individuals can come together, preferably with the blessing of one or both committees, and propose some practical, workable solutions for consideration by all parties.

Thank you.